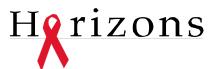
A Retrospective Assessment of the COPE 1 Program in Namwera, Malawi

Eka Esu Williams, Horizons

Joan Duncan, Consultant

Stan Phiri, Save the Children US/Malawi

David Chilongozi, Save the Children US/Malawi



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For further information:

Horizons Project Population Council 4301 Connecticut Avenue, NW Suite 280 Washington, DC 20008 USA

Tel: 202 237-9400 Fax: 202 237-8410

Email: horizons@pcdc.org www.popcouncil.org



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Executive Summary

Like other countries in Southern Africa, Malawi is experiencing an HIV/AIDS epidemic characterized by a high and rapidly growing rate of infection. To combat the problem, the government of Malawi promotes a decentralized, multisectoral response. For example, the National AIDS Control Program has established District AIDS Coordinating Committees and local AIDS Coordinating Committees to implement prevention and control strategies at the district and community level. In 1995 USAID/Malawi provided financial support to Save the Children US/Malawi from the Displaced Children and Orphans Fund to mobilize community action for the support of children, families, and communities affected by HIV/AIDS. This program, known as COPE 1 (Community-based Options for Protection and Empowerment), aimed to build on the government's decentralized approach to HIV/AIDS by strengthening these AIDS coordinating committees and catalyzing community responses to the problem. COPE 1 focused on three areas in Mangochi District: Mangochi Boma, Monkey Bay, and Namwera. This report focuses on the implementation and impact of COPE 1 in Namwera.

Working closely with the Mangochi District AIDS Coordinating Committee and the Mangochi District Social Welfare Office, Save the Children US/Malawi brought together representatives from government ministries, religious organizations, NGOs, and businesses in Namwera for a workshop on HIV/AIDS. This consultation led to the formation of the Namwera AIDS Coordinating Committee (NACC). Together with COPE mobilizers (Save the Children US/Malawi staff), the NACC worked in 16 villages to form Village AIDS Committees (VACs) made up of community leaders and concerned community members. The VACs were encouraged to work closely with existing community groups and health committees. Each VAC, like the NACC, formed four technical subcommittees and developed an action plan for a phased implementation of core activities, drawing on the support of COPE mobilizers. The subcommittees are orphan support, home-based care, youth, and high-risk groups.

Save the Children US/Malawi phased out its presence in Namwera in July 1997, seven months after it began working in the area. Given the limited documentation of COPE 1 and the interest on the part of Save the Children US/Malawi and donors to expand this initiative to cover a wider geographic area, a retrospective assessment of the program was carried out. Therefore, the Horizons Project worked with Save the Children US/Malawi to examine the impact of COPE 1 in

Namwera on the ability of communities to mobilize and sustain community-based responses to HIV/AIDS. The objectives of the study were to:

- Identify community perspectives regarding the roles, structure, and capabilities of the NACC and VACs and how they have changed over time.
- Assess the ability of the NACC and VACs to facilitate the continuation and expansion of activities initiated as part of the COPE 1 Program.
- Determine ways in which the communities have adapted and/or organized themselves to enhance their capacity to sustain COPE 1 activities.
- Determine the type of donor and government support that the communities consider to be important for facilitating and sustaining community-based HIV/AIDS activities.

Data were collected in November 1998 and in March 1999, more than one year after Save the Children US/Malawi phased out its activities in Namwera. The assessment used several methods of data collection, including group and individual interviews, review of reports and records, and observation. Residents from ten VAC villages and three non-VAC villages in Namwera were interviewed; respondents included VAC executive and technical subcommittee members, orphans, caregivers, youths, and village heads.

Findings

The link between HIV/AIDS and the growing problem of orphans and chronic illness was better understood in VAC villages than in non-VAC villages.

The connection between HIV/AIDS and the presence of large numbers of orphans and people with chronic illness was more often acknowledged by residents from VAC villages compared with those living in the non-VAC villages visited. While respondents in the non-VAC villages put the blame for the spread of HIV mainly on those traveling to or from the cities or Mozambique, in the VAC villages there is greater acknowledgment of locally practiced risk behaviors that are fueling the epidemic. In effect, the respondents in VAC villages do not blame others for the situation or expect to have others deal with the problem; they realize this is a community problem that they have to deal with through local effort and external support.

Unlike villages reached by COPE 1, villages without a VAC have not taken any tangible, collective action regarding the care and support of PLHA and orphans.

In the non-VAC villages visited, orphans and the chronically ill are still largely seen as the responsibility of the family. The health committees that are active in these villages focus on sanitation and immunization rather than on HIV/AIDS. In contrast, respondents in VAC villages, including members of the orphan and home-based care subcommittees, caregivers, and orphans, emphasize the community's responsibility to provide care and support to those affected or infected by HIV/AIDS. As a result of COPE 1, the VAC village subcommittees have provided emotional and material support to orphans, the sick, and their caregivers; fostered the social integration of orphans; conducted income-generating activities to benefit orphans and PLHA; and helped caregivers with household chores, such as doing laundry, providing water, and fetching firewood.

The NACC and VACs have lost credibility in terms of their coordinating and facilitating roles.

VAC and community members interviewed perceive the NACC to have been initially an important facilitator for mobilizing community members to participate in HIV/AIDS activities through the VACs. Support from COPE 1 enabled the NACC to provide highly appreciated training and materials to the VACs. Unfortunately, the NACC's inability to sustain these efforts has eroded its credibility and goodwill. Respondents feel that currently the NACC has inadequate capacity to respond to VAC needs, such as training and material support.

The VAC's leadership ability and degree of collaboration with the community are seen as important indicators of their effectiveness in catalyzing community responses to HIV/AIDS. From interviews and observation it is clear that some VAC leaders do not have the qualities or skills to run their VACs effectively. In addition there is some dissatisfaction about the process of how resources donated for use by the community have been distributed and utilized. To be effective, respondents believe that VACs need to seek the support of the village head, promote the participation of all community members, ensure that VAC members take part in planned activities, and take decisive action, particularly in transferring leadership.

Though many youth subcommittee members acknowledge initial support from the VAC and NACC, they are frustrated regarding their ongoing relationship with and support from them. For example, members receive very little feedback on the activity reports they provide to the NACC and VAC; the flow of communication has been inadequate. Promises to provide materials on HIV/AIDS, transportation, exchange visits, and sporting materials, such as footballs (soccer balls), have not been fulfilled. The NACC has not provided support for trained youth subcommittee leaders to conduct follow-up training of their members in leadership skills and HIV/AIDS as expected. In addition, youth subcommittee members also feel that some VAC leaders did not give the youth subcommittee the freedom necessary to make their activities more meaningful or to interact with individuals and groups whose input would be helpful. In addition, youth respondents feel that the NACC and VAC should support youth activities more visibly, which in turn would generate more interest among youth and their parents.

The orphan subcommittee is the most visible and recognized of the VAC subcommittees, but its accomplishments have been uneven.

According to respondents in VAC villages, since the formation of the VACs more families now openly discuss the problem of orphans and actively seek assistance. Respondents feel that the most successful activities undertaken by the orphan subcommittees have been the monitoring of the number of orphans in the community and their enrollment in school, and the distribution of seedlings and cuttings for communal farms whose proceeds provide some support for orphans. Weak activities include training orphan caregivers, monitoring school attendance, fundraising, and implementing income-generating activities. Food and monetary and material support to orphans and caregivers has been inadequate and inconsistent. Some orphans and caregivers have become disillusioned with VAC activities because they have not received any donations of food, clothes, books, pencils, and other supplies as promised. A recent drought and the resulting poor harvest have decreased community donations to orphans. Some orphan caregivers are old, poor, and unable to support orphans on their own. This category of caregiver has special problems that the subcommittees have not addressed. Despite many challenges, members of the orphan subcommittee believe that community support will continue because of the community's concern for the plight of orphans.

Youth subcommittees play a pivotal role in HIV/AIDS activities and are poised to do more.

The youth subcommittees in the VAC villages visited are generally well organized. They have regular meetings to identify and solve problems and a record is maintained of members, meetings, and activities conducted. Many young people report that they are motivated to work to prevent HIV/AIDS because they have seen "young, handsome boys and beautiful girls die of AIDS" in their villages. They are committed to spread messages about HIV/AIDS in an entertaining and participatory manner and to encourage orphans and vulnerable children to enroll and remain in school. Youth members have provided services to the sick, such as cleaning their surroundings, fetching water and firewood, and have also worked in communal gardens. They have played a valuable albeit undesignated role in helping orphans by raising funds to buy supplies for orphans. The orphans are themselves active members of youth subcommittees and have been encouraged by youth leaders to participate in their activities. Unfortunately, some activities of the youth subcommittees have discontinued because of a lack of materials and follow-up training. For example, many youth groups no longer play football (soccer) because their balls are worn out or have been lost. Youth members feel they could do more to support orphans and that they could conduct prevention activities, such as condom promotion, with additional support and training.

Home-based care subcommittees have remained active in VAC villages but morale is low because of the increasing number of ill people.

Home-based care subcommittees were found to be active in the VAC villages visited. Members report that they hold meetings two to four times per month. According to respondents, the strongest activities of the home-based care subcommittee have been visiting the sick, counseling those infected and affected by the disease, doing laundry, providing water, and fetching firewood. Facilitating the provision of material support, assisting with medical needs, and strengthening the skills of caregivers are considered weak activities. Many caregivers say they need to improve their caregiving skills and knowledge; they would also like to know whether the traditional methods and remedies they rely on for treatment are actually effective.

According to caregivers, who are overwhelmingly women, taking care of the chronically ill requires a great deal of time, patience, and support. The support provided by the VAC and home-based care subcommittee has not been adequate to meet their needs for materials, skills, medical

care, basic amenities, and time to attend to other needs, such as taking care of sick family members in cities such as Lilongwe or Blantyre. Some caregivers lack clear information regarding the cause of the patient's illness and what kinds of precautions they need to take. Unfortunately, issues of confidentiality and stigma are not directly addressed by the home-based care subcommittees. Many caregivers have lost their source of income because they provide care full time and lack the very access to financial support and skills development that would allow them to conduct income-generating activities from their homes. In general, the members of the home-based care subcommittee are discouraged because the problem is worsening and community support is on the wane.

The need for income-generating activities is great but inputs and expertise are limited.

Respondents highlighted the need for income-generating activities (IGAs), either as communal projects to raise money for support to orphans, the sick, and caregivers or as individual activities that caregivers can engage in at home. IGAs have been introduced by some VACs and have generally been managed by VAC executive members. Most IGAs have involved gardening and farming. While a few have been successful (e.g., one VAC organized the planting of beans and maize and sold these to buy soap, books, pencils, and salt for orphans, the sick, and the elderly), most have not been implemented or have been discontinued. In general, communities in which IGAs are working have strong VAC leadership, the involvement of the village head in the IGA, and labor donated by community members. Implementation problems have included inadequate monitoring and training by agricultural extension workers and lack of funds to acquire wetlands to allow planting crops year round. The future success of IGAs will depend on access to technical and financial support (e.g., agricultural extension, microfinance services), which has implications for the NACC, government agencies, and donors.

HIV prevention activities for high-risk groups are the weakest component of the COPE 1 Program.

There are several reasons for the lack of HIV-prevention activities by the high-risk group subcommittees. The terms of reference for the subcommittees are unclear and overlap with those of the youth subcommittee. Community residents have associated the subcommittee with

prostitution and, given that prostitutes are treated as outcasts, the subcommittee has become highly stigmatized and has not attracted members. Some respondents say that being a member of the subcommittee geared toward high-risk groups means promoting condom use, which many are not willing to do. In addition, the high-risk subcommittee has not been given much attention by the VACs in terms of training, allocation of resources, and support as compared with the other subcommittees. Despite these barriers, some youth subcommittee leaders continue to implement activities to reach those perceived to be at high risk for HIV/AIDS. These activities do not involve the distribution of condoms, although information about where condoms can be obtained is disseminated. Many respondents believe that youth are better placed to reach high-risk groups than adults and that the high-risk group subcommittee should be discarded and its activities should be integrated into the youth subcommittee. Others feel that the community needs to explore better ways of making the high-risk group subcommittee acceptable and functional, including changing the subcommittee's name to something less stigmatizing.

Views differ regarding whom donors should directly work with and support in order to generate community responses to HIV/AIDS.

The staff of Save the Children US/Malawi and members of the District AIDS Coordinating Committee (DACC) who are government employees feel that community programs need to be channeled through government structures, such as the DACC. However, they also recognize that this may encourage communities to have unrealistic expectations from government. In contrast, members of the NACC and VACs feel that donors should establish direct working relationships with their community-based organizations as opposed to higher-level government structures, such as the DACC. They believe that Save the Children US/Malawi's close involvement with the NACC and VACs under COPE 1 promoted collaboration and support among the groups involved and minimized feelings of distrust that might have occurred if the program was managed by government employees from elsewhere in the district.

The phase-out of COPE 1 in Namwera occurred too soon to build adequate capacity and trust.

Respondents consider seven months to be too short a period for the NACC and VACs to implement project activities in Namwera and to build adequate capacity for catalyzing additional

community responses. Although many report being aware that Save the Children US/Malawi planned to discontinue its support to the NACC, they feel there was too little time to implement the process properly. The NACC has not been sure about its post-COPE 1 role and responsibilities and the VACs have also been unsure about what to expect from the NACC. This has created some confusion and misunderstandings. For example, some VACs and community members believe that Save the Children US/Malawi has continued to provide materials to the NACC that are not being distributed to the community and that NACC members have been hired to replace COPE mobilizers.

Respondents feel that a concrete phase-out plan developed with input from the NACC and VACs would have helped to improve community coordination, sustainability, and trust. In addition, a strong local body to provide direction and support to activities at the community level would have minimized the disruption of phase-out. The NACC believes that it did not have the capacity at the time of the phase-out of COPE 1 to play this role nor does it have the capacity now. The NACC and VACs therefore favor a longer, more gradual phase-out followed by a one-year follow-up period to monitor community performance and to help solve ongoing problems. This additional time would allow the members of community structures to gain more confidence, acquire additional knowledge and skills, strengthen their networks with other groups, and exchange experiences with other VACs.

Conclusion and Recommendations

The introduction of a community-based program to address HIV/AIDS in the Namwera area by Save the Children US/Malawi, in collaboration with AIDS Coordinating Committees, has led to increased awareness and openness about HIV/AIDS, particularly with respect to the large numbers and needs of orphans and the chronically ill. More than a year after Save the Children US/Malawi discontinued their active support and presence in the area, the NACC and VACs appear to have sustained strong interest in and commitment to respond to HIV/AIDS as a result of the support and training they received under the COPE 1 Program. However, the roles and expectations of the NACC and VACs have become less clear and more uncoordinated during this period, creating some degree of distrust and loss of morale. Although some of the activities initiated through COPE 1 have continued to be implemented by the VACs, the communities lack the resources and skills to improve their performance or to meet new and growing needs at the

community level. The following recommendations emerged from the study and have implications for the NACC, VACs, government agencies, Save the Children US/Malawi, and other donors:

- Strengthen the leadership, decision-making, and community mobilization skills of the VACs because their abilities influence the effectiveness and sustainability of community responses to HIV.
- Promote more frequent communication between the NACC and VACs and a better definition of roles and responsibilities. Motivate the VACs and the NACC to provide mentoring and support to youth leaders.
- Assist youth subcommittees to sustain those recreational activities needed to attract and retain young people's participation.
- Identify acceptable ways in which to promote condom use and distribute information about accessing condoms.
- Encourage health providers to provide appropriate diagnosis and information to family members who care for patients with HIV-related illnesses.
- Facilitate networking between the home-based care subcommittees and existing health care provider groups in the community (e.g., village health committees, church groups, traditional healers) to increase support for PLHA and their families.
- Identify areas of collaboration for the home-based care, orphan, and youth subcommittees, particularly with regard to income-generating activities, to increase the community's ability to care for and support its sick.
- Review procedures for distribution of financial and material support to orphans, the sick, and caregivers to make sure they are transparent and equitable.
- Promote IGAs that have the best chance of success. Link VACs with appropriate technical support, such as agricultural extension, microfinance, and business development

groups. Foster exchange among VACs to identify ways of utilizing existing skills and resources for IGAs.

- Work with the VACs and communities to identify and implement feasible activities to reach those at high risk of HIV infection and determine how and by whom these activities will be carried out.
- Focus on providing inputs that have long-term impact, such as the development of skills required for carrying out HIV/AIDS prevention, care, and support activities.
- Use members from strong VACs and VAC subcommittees to share their expertise with newly organized VACs to ensure the utilization of valuable local resources and to boost the morale of the VACs.
- Involve the NACC and VACs in plans for phasing-out program activities by donors.

Introduction

Context of HIV/AIDS in Malawi

Like other countries in Southern Africa, Malawi is experiencing an HIV/AIDS epidemic characterized by a high and rapidly growing rate of infection among its population. Nationally, HIV prevalence is estimated to be over 13 percent and is as high as 35 percent among pregnant women in Blantyre. AIDS is now the leading cause of death among those 15 to 49 years old, and life expectancy is expected to decrease from a projected 57.4 years to 44.1 years by 2010. Recurrent health conditions associated with HIV/AIDS such as tuberculosis, the increasing number of pediatric AIDS cases, and a growing population of orphans and vulnerable children reveal the enormity of the health and social consequences of the epidemic. In 1996 the total number of maternal orphans under 15 years was 39,000, but this is expected to rise to 70,000 by 2005.¹

The national response to HIV/AIDS has been particularly visible in the concern shown to the plight of orphans by government and donor agencies. A National Task Force on Orphans was formed in 1991 with the involvement of the Social Welfare Department of the Ministry of Women, Children, Community Development and Social Welfare, UNICEF, and NGOs. The Task Force developed policy guidelines in 1992, which, among other provisions, defined an orphan as "a child who has lost one or both parents because of death and is under the age of 18." These guidelines reinforce the need for families and communities to take primary responsibility for the care and support of orphans, and recommend that institutionalization be a low-priority option for orphan care and support, with government being responsible for the coordination, supervision, and regulation of orphan services.

The government of Malawi promotes a decentralized, multisectoral response to HIV/AIDS. To facilitate this response the National AIDS Control Program established District AIDS Coordinating Committees and Community AIDS Coordinating Committees to implement prevention and control strategies at the district and community level. However, government employees responsible for the coordination of HIV/AIDS activities at the district level are often

¹ Ministry of Health and World Bank. (1998) Malawi AIDS Assessment Study. Report No: 17740.

overburdened with other pressing responsibilities and lack the resources to make these structures functional.

In 1995 USAID/Malawi provided financial support to Save the Children US/Malawi from the Displaced Children and Orphans Fund to mobilize community action for the support of children, families, and communities affected by HIV/AIDS. This two-year program (July 1995 – July 1997), known as COPE 1 (Community-based Options for Protection and Empowerment), aimed to build on the government's decentralized approach to HIV prevention, care, and support, particularly concerning orphans and vulnerable children, by strengthening the AIDS coordinating committees at the district and local levels, fostering community participation, and catalyzing community responses to the problem.

Overview of the COPE 1 Program

The development of the COPE 1 Program was preceded by a needs assessment conducted in Mangochi district in 1994 to determine the nature and extent of the needs of HIV/AIDS-affected children and families. Using the results of the assessment and a decade of experience working with vulnerable children, Save the Children US/Malawi designed the COPE Program with the following mission: "to improve the immediate conditions and long-term prospects for the care and healthy development of children affected by AIDS in three areas in Mangochi District (Mangochi Boma, Namwera, and Monkey Bay), promoting sound policy development and implementation alongside viable program interventions that can be adopted at the national level." This led to the establishment of activities aimed at mitigating the economic, health, and psychosocial effects of HIV/AIDS, which would depend on the full participation of community groups and members.

The COPE 1 Program was implemented in two phases. Phase one was an experimental pilot phase that provided lessons to guide the refinement of Phase two. Phase one activities were implemented in nine semi-urban villages around Mangochi Boma in Mangochi District. Three types of activities were implemented: economic activities, including group- guaranteed lending/savings and wetland garden support; health interventions composed of home-based care training, visitation, and referral of children under five for immunization, nutrition, and health-related services; and psychosocial interventions consisting of structured recreation activities, secondary school fees sponsorship, and vocational skills and nonformal education. These

activities were intended to benefit, in particular, families, chronically ill persons, including PLHA, orphans, as well as the entire community.

Phase two was a redesign of Phase one following a mid-term review in 1996 that emphasized three objectives: improving cost effectiveness, enhancing sustainability, and increasing scale.² Phase two was implemented from January to July 1997 in the area of Namwera in Mangochi District, adopting the AIDS coordinating committee structures that had been recently introduced by the government. The first step of Phase two was the mobilization of the community. Working closely with the District AIDS Coordinating Committee and the Mangochi District Social Welfare Office, Save the Children US/Malawi brought together representatives from government ministries, religious organizations, NGOs, and businesses for a three-day workshop. The groups discussed the epidemic and agreed that there was an urgent need for communities to act in order to mitigate its impact. This consultation led to the formation of the Namwera AIDS Coordinating Committee or NACC, made up of four technical subcommittees as recommended by the government: orphans, home-based care, youth, and high-risk groups.

In collaboration with COPE mobilizers (Save the Children US/Malawi staff), the NACC worked with 16 villages to form Village AIDS Committees (VACs), comprising community leaders and concerned community members. The structure of the different AIDS coordinating committees is shown in figure 1. The VACs were encouraged to work closely with existing community groups and health committees. Each VAC, like the NACC, included four technical subcommittees and developed an action plan for a phased implementation of core activities, drawing on the support of COPE mobilizers. These activities included:

- Identification, monitoring, and support of orphans and other vulnerable children.
- Home-based care training and visitation.
- Community fund raising.
- Distribution of farming inputs to vulnerable families (e.g., seeds, fertilizer and cassava cuttings).
- Formation of youth clubs.
- Organization of structured recreation activities for children.

² Williamson, J. and Donahue, J. (1996) Developing Interventions to Benefit Children and Families by HIV/AIDS: A Review of the COPE Program in Malawi for the Displaced Children and Orphans Fund.

Level **Figure 1: AIDS Coordinating Committees District District AIDS Coordinating Committee Namwera AIDS Coordinating Committee** (NACC) Area Orphan **Home Based Care (HBC)** Youth High Risk **Subcommittee Subcommittee Subcommittee Subcommittee Village AIDS Committees (VACs)** Village **Home Based Care (HBC) High Risk Orphan** Youth **Subcommittee Subcommittee** Subcommittee **Subcommittee**

Household

HIV/AIDS-Affected Children and Families and Other Vulnerable Community Members

To ensure coordination and effectiveness, the NACC was charged with supervising and supporting VAC activities, including the facilitation of training. The VACs were in turn expected to report their activities to and seek assistance from the NACC to deal with the problems they encountered. Community ownership was a central goal of COPE in Namwera in order to foster sustainability of the program. The key accomplishments under COPE 1 were the following:

- 16 VACs formed.
- NACC's and VACs' technical capacity to implement HIV/AIDS activities and foster community participation strengthened.
- District AIDS Coordinating Committee's ability to support the work of the NACC and VACs strengthened.
- Four technical subcommittees of the NACC and VAC formed for the management and coordination of activities (orphans, youth, home-based care, and high-risk groups).

Study Rationale and Objectives

Save the Children US/Malawi phased out its presence in Namwera in July 1997, seven months after it began working in the area. Given limited documentation and analysis of the outcomes of COPE 1 and interest by Save the Children US/Malawi and donors to expand this initiative to cover a wider geographic area, a retrospective assessment of the program was deemed important. Therefore, the Horizons Project worked with Save the Children US/Malawi to examine the impact of COPE 1 in Namwera on the ability of communities to mobilize and sustain community-based responses to HIV/AIDS. The study's objectives were to:

- Identify community perspectives regarding the roles, structure, and capabilities of the NAC and VACs and how they have changed over time.
- Identify community perspectives regarding NACC and VAC activities and reasons for their continuation or discontinuation.
- Assess the ability of the NACC and VACs to facilitate the continuation and expansion of activities initiated as part of the COPE 1 Program.
- Determine ways in which the communities have adapted and/or organized themselves to enhance their capacity to sustain COPE 1 activities.
- Determine the type of donor and government support that the communities consider to be important for facilitating and sustaining community-based HIV/AIDS activities.

Methodology

Data were collected in November 1998 and in March 1999 by local Yao-speaking interviewers. The assessment involved a number of qualitative methods, including:

- Informal group interviews.
- Key informant interviews covering a range of topics.
- Individual and group in-depth interviews focused on a few key topics
- Review of reports and records.
- Observation.

Representatives from ten VAC villages and three non-VAC villages in Namwera were interviewed. The VAC villages were: Balakasi, Chande, Chiutula Mitumbu, Kabuthu, Malayma, Milanda, M'menyanga, Ngawo, Simbiri, and Sumaili. The non-VAC villages were Maloa, Mwawo, and Mpamanda. Respondents included orphans, caregivers, youth, teachers, religious leaders, village heads, VAC and NACC executive committee members, and members of the technical subcommittees (see Appendix 1).

Respondents from VAC and non-VAC villages were asked about their perceptions of HIV/AIDS, the situation of orphans and sick people, and what was being done by the community to support orphans and the chronically ill. Community members living in VAC villages were asked more specific questions about the activities of the NACC, VAC, and their subcommittees.

Findings

Perceptions of the NACC

The VAC and community members who were interviewed perceive the NACC to have initially been an important facilitator for mobilizing community members to conduct HIV/AIDS activities through the VACs. They also acknowledge the NACC's effectiveness and credibility in forming the VACs; some respondents also highlight the NACC's role in facilitating material support for orphans and being a critical liaison between the communities and government as well as donors.

Support from COPE 1 enabled the NACC to provide training and materials (such as soap, clothes, blankets, maize flour, pencils, and notebooks) to the VACS that was highly appreciated. Unfortunately the NACC's inability to sustain these efforts appears to have eroded its credibility and goodwill. While the NACC was initially perceived as a facilitator of VAC activities, after the COPE 1 phase-out in Namwera the NACC took on the role of implementor by building a nursery school with donor funds. The opening of the Graziano Nursery School by the NACC created the perception in the minds of some respondents that the NACC was "doing its own thing" and had little time to respond to the needs of the VACs. However, the NACC has continued to stress the community ownership of the school, which provides free education to young orphans from all villages.

Because of perceived diminished support from the NACC, many VAC members express the need to maintain some degree of independence, to find ways to improve and develop their own capacity, and to take control of their own situations. It is also recognized that because the NACC is perceived by some to be an arm of government, communities have the right to demand more accountability from the NACC with regard to the provision of services to support their efforts. In sum, the VAC committee members interviewed feel that currently the NACC cannot adequately respond to VAC needs such as training, supervision, and material support.

According to the VACs a strong and effective NACC is one whose members have good leadership skills, conduct business transparently, respect divergent views, have prior experience in charity work and volunteer organizations, have a high level of awareness about the issues addressed, are diverse (e.g., religion, affiliation with government, the private sector), strongly represent the community, and are motivated to face the challenges of HIV/AIDS.

How the VACs Are Perceived

Most respondents perceive the VAC to be a coordinating and facilitating body for implementation of community HIV/AIDS activities by the village subcommitees. The VAC's role is considered to be central to the success or failure of community HIV/AIDS initiatives. The type and degree of collaboration with the community is seen by respondents as an important indicator of how effective a VAC has been in facilitating community responses to HIV/AIDS.

All respondents stress the need for a strong VAC to provide community leadership. Interviews with NACC, VAC, and community members provide a clear consensus on what constitutes a strong, effective VAC and what constitutes a weak, dysfunctional VAC.

Characteristics of a Strong VAC

- Holds meetings regularly, identifies problems, and implements solutions promptly.
- Has a well-defined plan of action to which it adheres and whose goals it tries to accomplish.
- Is able to mobilize different segments of the community for its activities and shares responsibilities with the community.
- Has the ability to network with other groups and individuals, especially the village head, to promote the work of the VAC.
- Responds to the needs of orphans and their caregivers.
- Is tolerant of divergent views, open and honest in its dealings, shows respect to members, and abides by the rules and regulations of the VAC.
- Solicits and uses feedback from the community and VAC members.

Characteristics of a Weak VAC

- Does not hold regular meetings.
- Has no clear plan of action, and does not follow its plan or accomplish its goals.
- Membership dwindles over time and members lack motivation.
- VAC members exhibit poor attendance in HIV activities in the community.
- Registers orphans and the sick but does not perform follow-up activities.
- Enrolls orphans in school but does not monitor their attendance in school, nor does it regularly visit orphans and the sick.

- Maintains a poor relationship with the village head.
- Mismanages funds and materials and has a leadership style that is not honest and open.

Based on interviews and observation, it is clear that some VAC leaders do not have the qualities or skills to run their VACs effectively. However, this study did not intend to evaluate the strengths and weaknesses of each VAC.³

Many respondents emphasize the need for VACs to work closely with village heads that have government-recognized authority and can address problems the VACs encounter from community members, such as lack of participation. VACs also need to be able to involve different groups in the community in order to increase the impact of their programs and foster community recognition and ownership of their activities.

Strong VACs have brought communities together to organize and share ideas on how to deal with the problems of orphans, the sick, and the vulnerable. However, it has been noted that VACs need to broaden their focus to include non-HIV/AIDS activities so that the people they care for and support are not stigmatized. An additional concern is the inadequacy of exchange between VACs and community members, especially in how donated resources for use by the community have been distributed or utilized. Better ways of promoting accountability are needed to gain the trust of the communities, particularly of youth groups, regarding distribution of financial and material support. The following recommendations to promote VAC effectiveness emerged from the study; these recommendations have implications for the NACC, other government structures, and donors:

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³ Further information about the capabilities and profiles of individual VACs can be found in the document, "Local Ownership of Problems and Solutions: An Exploratory Report on the COPE Project in Namwera" by Martin Hayes and Saed Wame, 1998.

RECOMMENDATIONS

- Help VACs to produce workplans and to monitor their activities.
- Identify areas of strength of each VAC and promote exchange between VACs to share these strengths.
- Assist communities to review current leadership of VACs in order to replace ineffective leaders and to strengthen leadership skills.
- Promote a process of self-evaluation among VAC leaders and subcommittees in order to become more effective.
- Help VAC subcommittees meet their training needs in areas such as home-based care, psychosocial counseling, and income-generating activities so that they can be more effective at the community level.
- Develop a mechanism for VACs to receive and utilize feedback from external reviews and exchange with other programs.
- Foster collaboration between VAC leaders, village heads, religious leaders, and community groups.
- Encourage VACs to better involve various community groups and to utilize local expertise in their activities.
- Promote guidelines to improve openness in leadership and the distribution of materials.

Perceptions of the VAC Subcommittees and Their Activities

Orphan Support: Respondents in VAC villages overwhelmingly acknowledge the increasing numbers of children orphaned because of parental death from HIV/AIDS, and express a great deal of concern about the well-being and future of these orphans. Young people, orphans, and adults consistently state that HIV/AIDS is the cause of the "orphan epidemic" in their villages. They note that many parents are dying: rich, poor, young, and old. Some worry that orphaned children will become a liability if they are not well cared for and properly integrated into the community. Specific concerns include a possible increase in crime, reduced opportunities for marriage for female orphans because of poor training in cultural values and domestic activities, and male orphans who lack farming skills. Compared with the past, respondents say that many families now openly discuss the problem of orphans and actively seek assistance as a result of the formation of the VACs. In non-VAC villages, there is general awareness of an increase in the

number of orphans. Although some attribute the increase to HIV/AIDS, others are not sure why there is a growing problem of orphans.

Community perspectives on care for orphans were solicited. One caregiver in a VAC village describes care and support to orphans using the Yao word *kalosya*, meaning "providing all necessities." These include water for bathing, shelter, food, school materials, and treatment during illness. Another equates this to "doing the kind of things that the parents of the orphans would do if they were alive." The need to pay attention to the specific needs of orphan girls and boys is emphasized -- training for girls should emphasize domestic chores, gardening, and preparation for marriage; boys need to focus on developing manual skills, in particular for farming. Some of the orphans interviewed in the VAC villages feel that they are obliged to show gratitude for the support the community provides. As a demonstration of their gratitude, some orphans say that they are determined to minimize antisocial and risk behaviors. They express the view that orphans need to practice good behavior to continue to earn the support of the community. According to one teenage orphan, "Some of us used to make trouble, and were heady when our parents were alive, but now we cannot make trouble for our caregivers and community because they have an interest in our future."

In non-VAC villages, orphans are cared for mainly by relatives, but poor care makes orphans easily distinguishable. Respondents note that orphans lack food, clothes, and shoes and are often teased by their peers. Although discrimination by teachers was not mentioned, it was reported that sometimes adults will say, "You look like a mad person." Orphans so far have not received any external support for school materials other than what caregivers have provided. There is no organized program to support orphans, and when families with orphans ask for assistance, a common response is: "I can't help because I also have problems of my own, so you solve your own problems." Many caregivers are weak, poor, and old themselves, and their problems have been compounded by a poor harvest. To support themselves, many caregivers, except the old ones, try to engage in odd jobs and trading. Without organized community support, orphans are under a lot of pressure. They worry about their dead parents and aging grandparents who are too old to do ganyu (casual labor) to support them. Although some of those interviewed are aware of the activities of VACs in other villages to help orphans, most have no knowledge of community-based orphan support activities. Both types of respondents are eager to have an orphan support program in their village.

Data from respondents in the VAC villages indicate that the orphan subcommittee is the most visible and recognized of the VAC subcommittees. Members' responsibilities included tracking the number of orphans in the community, monitoring their welfare, generating income for their support from the community and from specific income- generating activities, and maintaining a record of material donations made to orphans and their caregivers. In some villages members of the orphan subcommittee are divided into groups and, on a rotational basis, visit orphans and the sick, work in communal gardens, and facilitate other support activities for orphans.

Some orphan subcommittee members have been trained by the NACC in different aspects of care and support. They are expected to train orphan caregivers and to encourage fairness in the treatment and school enrolment of orphans by working with schools and adoptive families. Of all their designated activities, respondents feel that monitoring the number of orphans and their enrollment in school and distributing seedlings and cuttings for communal farms have been particularly successful. Other activities, such as distributing food and other material donations, training caregivers, monitoring school attendance, fundraising, and implementing incomegenerating activities have not been very successful. The key problems related to orphan support are summarized below:

PROBLEMS

- Food and monetary and material support to orphans and caregivers has been inadequate and inconsistent. A recent drought and the resulting poor harvest prevented many families from providing food to orphans.
- Income-generating activities have been small-scale and without the inputs necessary to ensure success. For example, compost (manure) and fertilizers are needed to improve the harvest from gardens and farms; however, the communities lack the skills to make compost and cannot afford to buy fertilizers.
- Some orphans and caregivers have become disillusioned with VAC activities because they
 have not received any donations of food, clothes, books, pencils, and other supplies as
 promised.
- Some orphan caregivers are old and poor and unable to support orphans on their own. This category of caregivers has not received the special attention it deserves.
- There has been a lack of transparency in the distribution of materials to orphans and caregivers.
- Orphan caregivers have had little access to credit, which they require to up small individual or group businesses (e.g., trading, brewing, sewing).

Interestingly, the youth groups have played a valuable, albeit undesignated role in promoting the support and social integration of orphans. Orphans are active members of youth groups and have been encouraged by youth leaders to participate in their activities, several of which have addressed HIV/AIDS prevention. By taking part in games, singing, and drama, some of the orphans interviewed say that they feel "more positive about life and do not have much time for self-pity." Youth club members feel that they could do a lot more to support orphans, such as monitoring school attendance and the treatment of orphans by caregivers. Members of youth groups are also prepared to volunteer more actively in income-generating activities to support orphans.

Despite several accomplishments, respondents express the need to do a lot more, especially given the escalating number of orphans in all villages. To improve care and support activities for orphans, respondents recommend several actions as follows, which have implications for the orphan subcommittees, VACs, NAC, and donors.

RECOMMENDATIONS

- Review local policies for material support and determine specific needs based on orphan gender and age.
- Broaden membership of the orphans subcommittee to include individuals with the interest and resources to care for and support orphans.
- Expand the activities of the youth subcommittee and youth groups to include orphan-related advocacy at the school and community level and monitoring of orphan welfare.
- Train youths to provide regular and specific types of assistance to elderly caregivers.
- Provide caregivers with skills to address the psychosocial needs of orphans and to promote gender-relevant and age-related skills and socialization
- Provide caretakers with skills and credit to generate personal income through small business activities.
- Establish a more open mechanism for distribution of materials to orphans and caregivers, for example, through community bodies other than the VAC.

Youth Activities: Youth clubs existed even before the formation of the VACs. These clubs agreed to become affiliated with the VACs so as to increase the scope of their activities, particularly with regard to HIV/AIDS. Prior to their involvement in the VACs, the groups played football and netball and organized traditional dances (e.g., Masewe). They saw an opportunity to expand their activities and receive training and material support through involvement with the VAC.

The youth subcommittees were found to be generally well organized. Many have regular meetings to identify and solve problems; they maintain a record of members, proceedings of meetings, and activities to share with the NACC and VAC. However, some youth subcommittees no longer share their information because of lack of feedback, encouragement, or support from the NACC.

Many young people report they are motivated to do HIV/AIDS prevention work because they have seen "young handsome boys and beautiful girls die of AIDS" in their villages and they believe that they have a responsibility to protect young people from HIV infection. Youth activities provide them with the opportunity to acquire new skills, understand one another better, and strengthen existing interactions and relationships. They are committed to spreading AIDS-prevention messages in an entertaining and participatory manner, and to ensuring that youth leaders encourage orphans and vulnerable children to enrol and remain in school. The youth interviewed regard the encouragement and support they receive from individuals and community leaders to be an acknowledgment of the importance of their work.

As a result of their involvement with the VACs, youth subcommittees have expanded the activities of youth groups to include drama, songs, and poetry that convey HIV/AIDS-prevention messages. These activities target the entire community and include all age groups. Members of the youth subcommittees also have informed the VACs about the orphans and sick persons in the villages, worked in communal gardens, and provided services to the sick, such as cleaning their surroundings and fetching water and firewood. In addition, youth members have contributed money or have used the money they raised to buy materials needed by orphans.

The youth subcommittee members said that they measure their success by tracking the number of people who attend their activities and are members of the subcommittee (particularly of girls), the number of parents who express interest in sending their children to youth activities, and by

feedback from community members. For example, one youth subcommittee started with 15 boys and 9 girls, but over 2 years the number of girls has increased to 19 and of boys to 21.

Unfortunately, the activities of some of the youth subcommittees have been discontinued because of a lack of materials and follow-up training as well as low morale. For instance, many of the clubs no longer play football because their balls have worn out or have been lost; the football field in one village has been converted to a garden because it was not being used.

Though many of the youth subcommittee members acknowledge initial support, there is some level of frustration regarding their relationship with and support from the VAC and NACC. For example, many youth subcommittee members say they receive very little feedback on the activity reports they provide to the NACC and VACs. The flow of communication is inadequate and promises to provide materials on HIV/AIDS, transportation, exchange visits, and sports supplies, such as footballs, have not been kept. The NACC has not provided support for trained subcommittee leaders to conduct follow-up training of their members in leadership skills and HIV/AIDS as expected. They also feel that some VAC leaders have not given the youth subcommittee the freedom to make their activities more meaningful or to interact with individuals and groups whose inputs would be helpful. According to one youth leader, this is the first time that youth subcommittee members in his village have spoken directly to a visitor without the VAC being involved or speaking on their behalf. Other key problems identified by respondents are summarized below:

PROBLEMS

- Lack of materials (e.g., balls) to attract and involve new members and meet set goals.
- Lack of attention to condom use: No facilitation of access to condoms by youth and of skills to promote condom use.
- Inadequate materials and information on HIV/AIDS to respond to information needs of young people.
- Poor access to training and information on HIV/AIDS.
- Loss of motivation and irregular attendance at meetings because of competing demands on young people.

Despite many problems, there is widespread acknowledgment of the potential impact young people could make on HIV prevention if properly trained and provided with the necessary resources. In addition, the youths interviewed express interest in addressing other areas of importance, such as drug abuse, teenage pregnancy, early marriage, creation of job opportunities, exchange of experience and skills, and in conducting outreach activities to non-VAC villages. Although they consider the quality and scope of their activities to be inadequate, they believe that young people in the community are beginning to change their behavior as a result of some of their efforts. For example, respondents think that more young people are abstaining from sex and fewer female students and female club members have become pregnant this year compared to previous years. Other perceived changes included the following:

- More young people are spending their time productively and are taking part in youth activities instead of idling as in the past.
- More young people are asking for information about where to obtain condoms (condoms have not been distributed by youth clubs members, but are sold in local drug stores).
- Boys who smoke "chamba" are doing so less often.
- School enrollment has increased and there is greater interest in schoolwork.
- Young people and their leaders are exhibiting more confidence.
- Girls have fewer sexual partners.
- Young people go out less at night and return home earlier.

The youth subcommittee members and other young people have identified a number of important roles for the NACC and VAC. Some feel that because of their experience and social standing, the NACC and VAC should more visibly support youth activities that in turn would generate more interest and support among youth and parents. They also believe that the VACs are suited to settling disputes among club members, encouraging parents to allow their children to participate in club activities, and organizing community-level income-generating activities that youth could participate in.

In some cases the study found that solutions to problems have been sought by the youths themselves. For instance, some youth subcommittees have solicited the support of village heads and VAC leaders to encourage parents to send their children to youth activities. Some youth members also have worked in tobacco estates to raise money to buy balls and support orphans or have raised money through drama performances attended by the community.

The following recommendations to strengthen youth subcommittee activities emerged from discussions with respondents:

RECOMMENDATIONS

- Identify and define roles and responsibilities of the NACC and VACs in relation to youth activities. Ensure that these leadership bodies take a greater interest in the activities of the youth subcommittee/clubs.
- Set up regular channels of exchange between the NACC, VAC, and youth leaders to enhance trust and communication.
- Identify other sources (e.g., national and provincial workshops) to provide skills to youth club members.
- Set up plans and activities to enhance greater youth participation in support of orphans, caregivers, and the sick, and for monitoring and advocacy.
- Assist youth subcommittees to sustain those recreational activities needed to attract and retain young people's participation.
- Facilitate networking between youth subcommittees and other youth groups that conduct reproductive health activities, including condom promotion, to share experiences and skills.
- Motivate the VACs and NACC to provide mentoring and support to youth leaders.
- Identify acceptable ways of promoting condom distribution and use through the activities of youth clubs.

Home-Based Care: In communities with VACs, there is a strong awareness of an increase in the number of people who are sick and whose illnesses tend to be chronic in nature. Traditionally, family members and other caregivers have looked after old people, the physically impaired, the mentally ill, and those with commonly recognizable diseases. However, more recently the number of sick people has become a major concern for the community. The problem has been compounded because traditional healers and caregivers do not seem to have the skills and remedies needed to deal with the situation. Also, the hospital staff is not providing the information necessary to help caregivers. According to a woman who is caring for a husband with a chronic illness: "Doctors and nurses talk about symptoms but not the disease." Many caregivers therefore are confused and worried because they do not know what they are dealing with.

Because of the large number of deaths of young people and of spouses, respondents in VAC villages attribute much of the illness and death to HIV/AIDS. This attribution is less frequently made in non-VAC villages where cholera and diarrhea were mentioned as frequently as HIV/AIDS. Some respondents in non-VAC villages note only that people are suffering from chronic and wasting illnesses. One village head reports not being aware of AIDS; another notes that he does not consider HIV/AIDS to be a major cause of death. Rather, he is more concerned about high levels of maternal mortality and death from "swollen legs," which is rampant. He says he is skeptical about the seriousness of the AIDS problem.

VAC home-based care subcommittee members and caregivers believe that the sick and elderly are part of any community and thus are the responsibility of those who have good health. The motivation to provide care is enhanced by a strong religious belief. Giving care is likened to *sadaka*, which in Islam means the giving of alms or in-kind support to those in need. Caring for others is believed to bring the community together and provides insurance for when one experiences illness oneself or needs support during important occasions, such as weddings and funerals. Caregivers consider their work to be important because those cared for are encouraged to live longer and know that their families and communities love them, which in turn decreases their feelings of isolation.

Home-based care subcommittees were found to be active in the VAC villages visited; members report that they hold meetings two to four times a month. The role of HBC subcommittee

members is to help caregivers build skills in nursing care, provide food and materials for patients, do day-to-day tasks, and arrange referrals for patients to hospital and clinics. Additional support for their work has come from health workers who are members of the community. In non-VAC villages, the community does nothing to provide care and support specifically to people living with HIV/AIDS. The health committees that are active in these villages focus on sanitation and immunization rather than HIV/AIDS. Some respondents are aware that neighboring villages have mobilized themselves to care for the sick and this is considered a good idea and something they would like to undertake.

Those HBC activities that respondents in VAC villages consider to be strong are making visits to the sick, counseling those infected and affected, making referrals, doing laundry, providing water, and fetching firewood. Facilitating the provision of material support, such as food and clothes, and assistance with medical needs are considered weak. Another weak area is strengthening the skills of caregivers; many caregivers express the need for more information and better skills in providing care as many of them have not received any training. In addition, they would like to know whether the traditional methods and remedies they rely upon are effective in meeting the needs of the chronically ill.

According to caregivers who are overwhelmingly women, taking care of chronically ill patients requires a lot of time, patience, and support. The support provided by the VAC is considered to be far from adequate in addressing their problems, which include lack of materials, skills, medical care, basic amenities, and time to attend to other needs. The AIDS situation is critical and according to a key informant, "AIDS will stretch our resources to the limit in the near future and we urgently need to mobilize more hands and resources to prepare for the problem ahead."

Caregivers report that they experience an extra burden when they have to travel to Lilongwe or Blantyre to care for their relatives with HIV/AIDS and their relatives' children. They lament the lack of care and support for PLHA in urban areas and the stigma associated with the disease. Transportation costs, loss of income, and support to sick relatives quickly deplete the meager resources of caregivers. Funeral costs and support to orphaned children from the cities are also immediate concerns to deal with following the death of an urban-dwelling relative. Key problems reported by caregivers and HBC subcommittee members are summarized below:

PROBLEMS

- Many caregivers have lost their own source of income because they provide care full-time.
- Caregivers lack access to financial support that would allow them to conduct small incomegenerating activities from their homes.
- Many caregivers have limited access to food and essential materials because they depend on community members who are hardly able to meet their own needs.
- There is a water shortage and caregivers need to travel long distances to fetch water.
- Caregivers lack clear information regarding the illness of the patients they care for and what kinds of precautions they need to take.
- Data collection is scanty and HBC and VAC members barely know how to use the data they
 do collect to improve home-based care.
- HBC subcommittee members need appropriate skills and material support to train caregivers and to meet the expectations of patients and families.
- PLHA and family members are unwilling to talk about the nature of the illness for fear of being stigmatized. Confidentiality and stigma have not been addressed by the HBC subcommittees, the NACC, and VACs.
- HBC subcommittee members are discouraged because the problem is growing and community support is dwindling.

Some caregivers report having found ways of depending on each other to care for patients in order to free themselves for other essential activities, such as farming, going to the market, or even sleeping. In addition, some women caregivers report pooling their money to buy goods that they then sell and of subsequently sharing the proceeds. Others say they sometimes share food with other households to ensure that caregivers and patients do not starve.

A wide range of recommendations emerged from discussions with respondents. These recommendations aim to improve communities' abilities to deal with the growing problem of caring for PLHA in their homes and are addressed to the HBC subcommittees, VACs, NACC, the health sector, and donors.

RECOMMENDATIONS

- Provide appropriate diagnoses and information to family members and caregivers caring for patients with HIV-related illnesses.
- Coordinate the activities of HBC subcommittee members, caregivers, and village health committee members to improve services and support to the sick.
- Strengthen the role of HBC providers by improving networking with existing care provider groups (e.g., health committee members, church groups, traditional healers).
- Provide small loans or financial support to enable caregivers to earn income.
- Encourage and support the NACC to work with other groups to provide the needed training for HBC members and caregivers.
- Assist caregivers to organize inter-family support to free time and pool resources to address each other's needs.
- Identify areas of collaboration for the HBC, orphans, and youth subcommittees, particularly with regard to income generating activities, so as to increase their effectiveness in caring for and supporting the sick.

Income-Generating Activities: Income-generating activities (IGAs) have been introduced by some VACs as a way of providing economic support to the sick, the elderly, and orphans. The aim of the IGAs is to engage community members to work together to provide food, plant cuttings, and seeds to the needy, and to procure and distribute essential items such as soap, salt, and blankets through the sale of materials from IGA activities. The VACs have stressed the connection between being able to raise local resources and income and being able to provide support to those in need. IGAs provide a practical approach for fostering inter-VAC subcommittee collaboration and involvement of community members. Communal gardens, for example, attract community participation because community members see the direct benefit to be derived in supplying food and seedlings to the needy.

Most IGAs have involved gardening and farming. Working closely with their VAC, community members in one village contributed money (about US 50 cents each) to buy land for a communal farm. Owning a sizable amount of farmland means they can seek farming inputs and technical assistance from agricultural extension workers to grow additional crops.

IGAs have generally been managed by VAC executive members who act as the IGA subcommittee. Where IGAs seem to be working successfully, there is strong VAC leadership, the provision of free labor by community members, and close involvement of the village head. However, there have been numerous challenges associated with IGAs, including gardening and farming efforts -- activities that community members believe they have the required skills to perform. Many IGAs are never put into practice or are discontinued, such as fish-farming, and poultry and small business ventures; the key problems and limitations are as follows:

PROBLEMS

- Monitoring and training by agricultural extension workers have been inadequate, particularly for making compost, use of fertilizers, crop rotation, and pest control.
- Community members' lack of farming and management skills to grow crops for cash, such as tobacco, or for local consumption like fish-farming, have not been addressed.
- VACs lack support and resources to acquire wetlands to allow year-round gardening and farming.
- VACs are unable to procure enough farm land for their needs and planned activities.

It was difficult to determine what financial and material benefits the VACs have derived or expect to make through IGAs because many have only just started or the scale of activity is small. However, one VAC that planted short-season crops (e.g., beans and maize) sold these to buy soap, books, pencils, and salt, and have made donations three times to the orphaned, the sick, and the elderly. Another VAC provided vital materials to orphans and patients at the Sister Martha Hospital through the sale of their farm produce. Other crops such as cassava have been grown in other communities but are yet to be harvested. Recommendations for improving IGAs were as follows:

RECOMMENDATIONS

- Promote exchange among VACs to identify ways of utilizing available skills and resources for IGAs.
- Strengthen the capacity of VACs to manage and implement IGAs through appropriate training.
- Link VACs with micro-credit and business development groups to provide needed capital and training in credit management and small business development.
- Promote IGAs that community members would have a better chance of success with, such as farming, and provide needed technical support (e.g., compost production, crop rotation, pest management).
- Identify potential outlets for the sale of farm produce as a way to encourage communities to set and meet targets.
- Identify better ways of increasing and sustaining the involvement of community members and village heads in IGAs.
- Assist communities in developing effective, low-tech measures to control pests and to preserve farm produce for the market.
- Help VACs procure more farmland and assess the ability of VACs to work together to implement a joint venture through the growing of cash crops.
- Engage the support of the NACC for IGAs because it is well placed to seek and negotiate external support and resources for such activities. Without such involvement, projects are less likely to be successful.

High-Risk Group Prevention Activities: By far, the weakest component of the COPE 1 Program has been HIV-prevention activities for high-risk groups. Several reasons were given for the weakness of this component during discussions with NACC and VAC members. Firstly, the terms of reference for what the high-risk subcommittee should do and how it should operate have been unclear and overlap with those of the youth subcommittee. Secondly, the name of the subcommittee has a negative connotation. For example, in one community residents associated the subcommittee with prostitution and, given that prostitutes are considered to be outcasts, the subcommittee is highly stigmatized and has not attracted many members. Third, some respondents say that being a member of the high-risk subcommittee means promoting condom use, which many are not willing to do. A fourth reason is that the high-risk subcommittee has not been given much attention by the VACs in terms of training, allocation of resources, and support compared with the other subcommittees. This may have been because of the perception

that a high-risk subcommittee is only necessary in Namwera town where "risk groups" are more easily identified. But some respondents note that "risk groups," such as traders, drivers, widows, sex workers, women who brew alcohol, farmers who sell their produce in towns, and young people are found in both rural and urban areas and therefore need to be reached. Despite these barriers, some youth subcommittee leaders report conducting activities to reach those perceived to be at high risk. These activities have not involved the distribution of condoms, although information about where condoms can be obtained is given. There is a strong feeling among respondents that the youth subcommittee members are better placed to reach high-risk groups than adult members of other VAC subcommittees.

It appears that the idea of a high-risk subcommittee is yet to be widely accepted by the VACs and communities. There are two views concerning how to resolve the situation. Some suggest that the subcommittee be discarded and its activities be integrated into the youth subcommittee; others feel that the community needs to explore better ways of making the subcommittee acceptable and functional, including changing the subcommittee name to something less stigmatizing.

Several recommendations were made to reach those at risk more effectively. These were:

RECOMMENDATIONS

- Identify specific activities that are feasible and acceptable, and the channels and strategies for their implementation.
- Assess the potential for integrating high-risk group interventions into activities of the youth subcommittee and youth groups.
- Develop culturally sensitive ways of increasing access to condoms and build skills for condom promotion and use.
- Promote advocacy to reduce stigma against groups perceived to be at risk.
- Provide training and support to members of key groups such as sex workers and drivers, to conduct educational outreach activities with their peers.

Key Criteria for Community-Based Interventions

The COPE 1 Program placed a great premium on the need for communities to assume leadership for and ownership of activities, and to work in partnership with stakeholders in order to ensure quality and sustainable programs. The following findings include community perspectives on how to strengthen these critical elements in order to foster an effective community response.

Leadership: Respondents' ideas for improving leadership focus on the selection of leaders and the involvement of the community. Strong leadership is regarded by respondents as an important element for the continuity and success of NACC and VAC activities. Given that the individual capabilities of committee leaders affect the communities' perception of the NACC and VAC, it was suggested that leaders be drawn from groups whose members already have local credibility and professional expertise in leadership, such as religious groups, village funeral committees, political parties (to give official but nonpartisan support), farmers' groups, and village health committees. But regardless of where they are recruited from, clear criteria are necessary for choosing those aspiring to leadership positions in the VAC and NACC so as to reduce the chances of failure due to poor leadership.

Once they have been selected, respondents identified some examples of what leaders need to do to ensure success. These include soliciting the support of the village head, promoting the participation of community members in VAC activities, and ensuring that VAC members participate in all activities. Moreoever, it is considered critical that VAC members take decisive action, particularly as regards electing new leaders and removing ineffective ones. For example, some leaders have been unsuccessful in promoting VAC activities, but continue to be in charge of the VAC.

Ownership: According to respondents, community problems need to be identified and tackled by the community if communities are to take their problems seriously and try to address them. Acknowledging a problem gives urgency to it and generates support from everyone, whether or not they are friends or relatives of the one affected. According to a key informant, "When the community owns an HIV/AIDS program, they work hard to make it succeed and to solve problems that arise through their own effort."

In Namwera, a sense of ownership has been hinged on the belief that orphans and sick people belong to the community and that the community has the responsibility to support them. In adverse situations, such as during funerals and illness, communities come together to provide support. Some members of the VAC feel that taking on these responsibilities is only possible when the VAC is strong and has good leadership. VACs with effective leaders instill a sense of ownership of the program that results in community members looking inwards to find solutions to problems rather than waiting for outside assistance. The study found a number of examples of the community assuming ownership of an activity and moving ahead on their own, such as raising funds to support orphans and training youth members on HIV/AIDS, despite the lack of continued training and financial support from the NACC.

Community Participation: The NACC and VACs recognize the need to promote community participation in order to generate resources, recruit volunteers for IGAs, and sustain activities. Those VACs that have been able to continue their activities emphasize the importance of involving community members, groups, and leaders. However, they stress the need to keep participation voluntary to ensure that those who take part do so because they are committed to the cause of the community.

The participation of religious and political leaders and of community groups already addressing care and support in VAC activities is recommended because of their credibility, experience, and the roles they play in the community. The ability to foster and achieve broad participation is seen as a mark of success and acceptance of the activities by the community and is an indication of the likelihood for continuity. VAC subcommittee members who tend to do the work themselves have accomplished little and have had poor response from the community whereas VACs who encourage community participation undertake more activities and gain the support of the community. Several ways of encouraging community participation have been mentioned. The youth subcommittee, for example, has used the Chairman of the VAC to solicit the support of parents to allow their children to attend youth activities. To enhance community participation in IGAs, some VACs have engaged the support of the village head.

Partnership with Government and Donor Involvement: Respondents express different views regarding whom donors should work directly with and support. Members of the District AIDS Coordinating Committee (district-level government employees) and COPE Program managers (Save the Children staff) feel that community programs need to be channeled through government

structures. But they also feel this may create undue expectations of government by the communities. Given government's limitations in meeting the many needs of communities, these respondents have concluded that communities first need to define their priorities, and mobilize local resources. The next step is for them to collaborate with government so that government staff already working in communities, such as community development assistants, agricultural extension officers, and health committee members, can provide technical assistance and targeted financial support.

In contrast, members of the NACC and VACs feel that donors should establish direct working relationships with the NACC and VACs as opposed to high-level government agencies. Because Save the Children US/Malawi worked closely with the NACC and VACs under COPE 1, collaboration and support was established among the groups and minimized feelings of distrust that might have developed if the program was managed by district government officials from Lilongwe or Blantrye. Some VAC members stress that while it was important for Save the Children US/Malawi to work and reach decisions with the NACC, it was also necessary for them to keep the VACs directly involved in and abreast of major decisions. In addition, they emphasize that donors need to be selective in their support and should focus on inputs that have long-term impact, such as the development of skills required for HIV/AIDS activities.

Sustainability of Activities: Many VAC members interviewed are in the process of planning or implementing activities that would enhance their ability to sustain HIV/AIDS programs. Sustaining activities and expanding them to meet the needs of the community are a great priority. IGAs, such as community gardens and farms, and small businesses are important ways of sustaining HIV/AIDS activities. The VACs with small gardens are hoping to acquire more land to grow staple crops, such as maize, and cash crops, such as tobacco, which would yield more money. Some VACs hope to acquire wetlands and to set up fish farming. The success of these activities will depend on improved skills and supervision from agricultural extension workers. Better use of local skills and resources and enlisting more volunteers were also cited as additional ways in which to promote the sustainability of agricultural activities. Dependence on outside facilitators and resources for training was noted as neither appropriate nor sustainable and respondents stress the need to develop community-based expertise for training.

Generating new ideas and seeking advice from community members were mentioned as ways in which VACs can sustain community interest and involvement in VAC activities. Gaining the

support of village heads would promote sustainability as they would be effective in mobilizing community involvement and support. In the area of orphan care, the support of village heads was seen as crucial for facilitating community dialogue and consultation for soliciting continuous food and material donations. Because many of these activities bring credit to the village head and the community, the involvement of the village head is beneficial for both parties. Promoting the transfer of skills and responsibilities from older to younger members of the community was identified as another important approach to sustaining activities. Sustaining VAC activities is the only way communities believe that they can ensure that orphans will be cared for and encouraged to remain in school.

The VACs suggest various ways in which the NACC can facilitate sustainability. Its members can act as advisors, resolve conflict, provide moral support, and technical assistance, as well as conduct training, monitoring, and evaluation. Also, the NACC needs to interact directly with the community to obtain their feedback and to advocate support for VAC activities.

In general, members of the orphan subcommittee feel that community support will continue because of widespread concern for the plight of orphans. Apart from the many activities they hope will generate income, they see the high level of commitment, motivation, and optimism of their members as critical elements for sustainability. This is in contrast to the home-based care and high-risk subcommittees whose members generally have low morale. Although energized in general, members of the youth subcommittees feel the need to better organize these subcommittees and increase the level of unity among members as key to the continuation of their activities. The resumption of village and inter-village activities such football and netball that bring many young people together would enhance sustainability.

Program Phase-Out

Many consider seven months to be too short a period for the NACC and VACs to implement project activities in Namwera and build adequate capacity to catalyze additional community responses; minimum of a year is believed to be more adequate. Although many report knowing that Save the Children US/Malawi planned to discontinue its support to the NACC, it is felt there was little time to implement the process properly. The NACC was uncertain of what its post-COPE 1 roles and responsibilities would be, and the VACs have been unsure of what to

subsequently expect from the NACC; this has created some false impressions. For example, some VACs and community members suspect that Save the Children US/Malawi has continued to provide materials to the NACC that are not being distributed to the community and that NACC members have been hired to replace COPE mobilizers.

A concrete phase-out plan, developed with input from the NACC and VACs, would have helped to improve community coordination and enhance sustainability and trust. In addition, a strong local body that would continue to give direction and support to activities at the community level would have minimized the disruption of the phase-out. The NACC believes that it was not an effective enough body at the time of the phase-out of COPE 1; even today, it feels it does not have the capacity to play that role.

Although the NACC had a 3-month period to prepare for phase-out and was given well-defined parameters by Save the Children US/Malawi about what the transition would entail, NACC members perceive the time to be inadequate. Although they acknowledge that post phase-out visits by Save the Children US/Malawi and the donation of bicycles to support the NACC have been useful, there remained a critical unmet need for training. Therefore, the NACC and VACs favor a longer, more gradual phase-out followed by a one-year follow-up period to monitor community performance and solve ongoing problems. This additional time would allow the members of community structures to gain more confidence, acquire additional knowledge and skills, strengthen their networks with other groups, and exchange experiences with other VACs.

Conclusion

The introduction of a community-based program to address HIV/AIDS in the Namwera area by Save the Children US/Malawi, in collaboration with AIDS Coordinating Committees, has led to increased awareness and openness about HIV/AIDS, particularly with respect to the needs of the large numbers of orphans and the chronically ill. The connection between HIV/AIDS and the presence of large numbers of orphans and people with chronic illness is more often acknowledged in VAC-villages compared with non-VAC villages. Respondents in VAC villages, including orphans, members of home-based care subcommittees, and caregivers emphasize the community's responsibility to care for and support those affected or infected by HIV/AIDS whereas in non-VAC villages, orphans and the chronically ill are still largely seen as the responsibility of the family. Unlike villages reached by COPE 1, villages without a VAC, though generally aware of HIV/AIDS, have not taken any tangible collective action to address the problem in terms of HIV prevention or care and support of PLHA. While non-VAC villages put the blame for the spread of HIV mainly on those traveling to or from the cities or from Mozambique, in the VAC villages there is greater acknowledgment of the risk behaviors occurring locally in villages that are fueling the epidemic. In effect, the VAC villages do not blame others for the situation or expect to have others deal with the problem; they realize this is a community problem that they have to deal with through local effort and external support.

More than a year after Save the Children US/Malawi discontinued its active support and presence in the area, the NACC and VACs appear to have sustained a strong interest and commitment to respond to HIV/AIDS as a result of the support and training they received under the COPE 1 Program. However, the roles and expectations of the NACC and VACs have become less clear and more uncoordinated during this period, creating some degree of distrust and demoralization. Although some of the activities initiated through COPE 1 have continued to be implemented by the VACs, the communities lack the resources and skills to improve their performance or to attempt to meet new and growing needs at the community level. For instance, youth subcommittee members want to promote and create access to condoms and to address issues that are of importance to young people, such as reproductive health education and services, prevention of early marriage for girls, and vocational training.

The VACs identified several priorities for improving and sustaining program activities. These include strengthening the leadership of the VACs, especially since respondents attribute program

weakness to poor leadership, and capacity building through training. Several VAC subcommittee members have not participated in a single training session. Respondents emphasize the importance of developing capacity to provide training locally (without external trainers) and using local resources and expertise in areas such as compost production, crop rotation, and use of traditional treatment methods and remedies. Given the NACC's commitment to set up VACs in all villages in Namwera, an appropriate strategy would be to use members from strong VACs and VAC subcommittees to provide assistance and to share experience with newly organized VACs. Many VAC members believe that this would not only ensure the utilization of valuable local resources, but would boost the morale of the VACs. For example, youth subcommittee members would be a good resource for mobilizing young people in other villages to start HIV/AIDS prevention activities that target youth.

A key area of concern is the lack of strong high-risk group subcommittees. In the Namwera area, several reasons have made it difficult for this subcommittee to function. This presents a dilemma because community members are convinced of the need to reach those at "high-risk," yet most have not yet taken an active role in addressing the problem with the exception of some youth subcommittee members. Further discussion needs to occur at the community level to determine the need for a specific high-risk group subcommittee or to identify alternative mechanisms and strategies for reaching groups at risk of HIV/AIDS.

The results from this retrospective assessment of the COPE 1 Program provide valuable lessons for expanding this model, strengthening existing VACs, establishing new VACs in Nawmera, and fostering exchange with other community-based programs within the country, especially with regard to improving community-based orphan care and support, youth interventions, and community mobilization activities.

Appendix 1: Study Villages and Respondents

Sumaili: Group interviews

(VAC village) VAC executive committee

Subcommittee members (youth and orphans)

Caregivers
Orphans
Youth

In-depth interviews

Home-based caregivers

Orphans Youth

VAC Secretary

Malayma Group interviews

(VAC village) VAC executive committee

Subcommittee members (youth and orphans)

Orphans
Caregivers
Youth

In-depth interviews

Income-generation activity members

Orphans

M'menyanga: Group interviews

(VAC village) VAC executive committee

Subcommittee members (orphans and home-based care)

Orphans
Caregivers
Youth

Balakasi: In-depth interviews

(VAC village) Subcommittee members (home-based care)

Orphans

Simbiri: In-depth interviews

(VAC village) Income-generation activity members

Youth

Ngawo: Key informant interviews

(VAC village) VAC chairman

VAC secretary

In-depth interviews

Income-generation activity members

Subcommittee members (home-based care)

Namwera Town: Key informant interview

Village headman

Kabuthu: Group interviews

(VAC village) VAC executive committee

Subcommittee members (?)

Chiutula Mitumbu: Group interviews

(VAC village) Caregivers

Sheikhs

Community members

Chande: Group interviews

(VAC village) Caregivers

Christian and Muslim leaders

Orphans

Jalasi Youth Club: Group interview

Malowa Village: Key informant interviews

(non-VAC village) Village headman

Village secretary

Mwawo Village: In-depth interviews

(non-VAC village) Religious leaders

Mpamanda Village: Group interviews

(non VAC village) Caregivers

Orphans

Religious leaders and headman counselor

Youth

In-depth interviews

Caregivers

In-depth interviews:

COPE manager

DACC Secretary

NACC Secretary